

How informal caring affects older people

Andy Ross, Michael Weinhardt and Hayley Cheshire (NatCen)
James Lloyd (International Longevity Centre–UK)



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Older people (aged 50-plus) who devote 20 or more hours a week to caring for family or friends have a poorer quality of life than non-carers, according to the report ‘Living and Caring’ produced by the National Centre for Social Research (NatCen) and the International Longevity Centre UK (ILC-UK). The research was funded by the Nuffield Foundation and based on evidence from the English Longitudinal Study of Aging (ELSA).

- With the demand for personal care forecast to rise as the UK population ages, more increasingly older people are expected to care for family members and friends. This report examines how informal caring affects the lives of older people.
- Two factors significantly influence the experience of older carers: the amount of time they spend caring (we distinguish between ‘light’ and ‘moderate to heavy’ care); and their relationship to the person they care for (a spouse, a child, or a parent/parent-in-law).
- On average, older carers who provide moderate to heavy levels of care (ie, 20 or more hours a week) to either a spouse or a child have much lower levels of family wealth than non-carers.
- Carers providing moderate to heavy levels of care to a spouse, a parent or a parent-in-law, find it harder to carry out everyday tasks such as visiting a GP, getting to the hospital or even shopping.
- Caring is associated with taking less holidays, both abroad and in the UK, and going on outings or day trips. It also seems to hinder other leisure activities such as going to the cinema or eating out.
- When an older carer looks after their spouse, it is a partner’s poor memory which seems to have the greatest detrimental effect on their well-being, more than a spouse’s physical care needs, health, or the number of care hours involved every week.

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Demand for informal care is on the rise

As the average age of the UK population increases, demand for all forms of personal care is expected to rise. It is also expected that the majority of this care will continue to be provided informally by friends and family, and to fall increasingly on older generations.

A new study by NatCen and the ILC-UK assesses the impact of informal care provision on older people by comparing the experiences of carers and non-carers aged 50-plus across five key social policy domains:

- income and work;
- mobility and access to services;
- participation in leisure and community activities;
- health;
- housing.

The study, which uses evidence from Wave 2 (2004) and Wave 3 (2006) of the English Longitudinal Study of Ageing (ELSA), also examines the quality of life of carers.

Older carers are not a homogenous group

Of the 10 per cent of people aged 50 or over who were carers at the time of the ELSA (2004) survey:

- 39 per cent were caring for a spouse or partner;
- 34 per cent for a parent or parent-in-law;
- 24 per cent for another relative, friend or other person;
- 11 per cent for a child.

Two factors significantly influenced the experience of carers: the amount of time they spent caring; and their relationship to the person they cared for. For this reason we distinguished between those providing 'light' levels of care (up to 19 hours a week) and those providing 'moderate to heavy' levels of care (20 or more hours a week); and between those caring for a spouse, for a child, and for a parent or parent-in-law. Figure 1 (below) sets out the six different carer groups.

Figure 1. The six carer groups

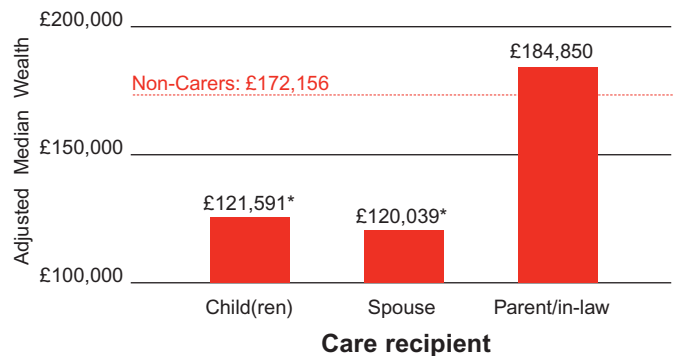
Care burden	Care recipient		
	Spouse	Child(ren)	Parent/in-law
Light (0-19hrs pwk)			
Moderate to Heavy (20+hrs pwk)			

Caring is directly associated with financial loss

There were some clear differences in the levels of personal income and family wealth between carers and non-carers. For example, people providing moderate to heavy care for a spouse or a child had much lower levels of family wealth than non-carers on average. Family wealth includes all non-pension assets (ie, property,

business assets, antiques, etc.) As Figure 2 (below) shows, those caring for a child had a median wealth of £121,591 and those caring for a spouse had £120,039, whereas non-carers had an average wealth of £172,156.

Figure 2. A comparison of the family wealth of 'moderate to heavy' carers and non-carers (2004)



*Indicates a statistically significant difference from non-carers (significant at 5 per cent)

The potential loss of income involved in becoming a carer was also shown by the differences between those who became carers and those who remained non-carers during the course of the research. On average, people who became carers between 2004 and 2006 experienced a significant reduction in personal and family earnings, as well as total family income, whereas the income of those who remained non-carers over the same period remained stable, or increased. Although further research is necessary to determine if becoming a carer *causes* a loss in income, we can conclude that becoming a carer seems to be *directly* associated with financial loss.

Many older carers have trouble accessing services

Some carers reported difficulty accessing a range of public services, especially health-related services. 25 per cent of those providing moderate to heavy care to either a spouse, a parent or a parent-in-law found it hard to get to a hospital, compared to just 10 per cent of non-carers. And 21 per cent of those caring for a parent or parent-in-law had trouble getting to a GP, compared to just 2 per cent of non-carers. Both groups were more likely to find it hard to visit an optician or go shopping.

Since carers and non-carers had equal access to a car and made similar use of public transport, it seems likely that it was limited time rather than specific transport issues that hindered many older carers from accessing services.

Many older carers lose out on holidays and leisure

People caring for a spouse were far less likely to have taken a holiday in the UK in the previous 12 months than non-carers. Just 40 per cent of those who provided light care, and 34 per cent of those who provided moderate to heavy care, had taken a UK holiday, compared to 58 per cent of non-carers. People providing moderate to heavy care for a spouse were also considerably less likely to

have taken a day trip in the UK during the same period (48 per cent compared to 65 per cent of non-carers) and significantly less likely to have enjoyed a foreign holiday (24 per cent compared to 48 per cent of non-carers).

Carers were also more likely than non-carers to feel restricted in their leisure activities. For example, when asked about recreational activities, carers were more likely than non-carers to feel they couldn't go to the cinema as often as they'd like. People providing moderate to heavy care for a spouse were also more likely to feel unable to eat out as often as they would like (60 per cent compared to 42 per cent of non-carers), and those caring for a child or providing moderate to heavy care for a parent or parent-in-law felt less able to visit art galleries or museums.

Health issues for older carers

Comparing the health of carers and non-carers showed that carers were healthier than non-carers, on average, which suggests that good health may be a prerequisite for caring for others, at least among older carers. The exception was that people providing moderate to heavy care for a spouse were slightly more likely to report trouble with some physical tasks (eg, walking 100 yards, stooping, kneeling or crouching). Importantly, carers reported a higher capability than non-carers for tasks associated with everyday living (eg, preparing a hot meal, managing money).

Furthermore, between 2004 and 2006, the average number of self-care tasks (ie, dressing, washing) that caused problems for individuals remained consistent for those who became carers, stayed carers or stayed non-carers during the course of the research, whereas it increased slightly among those who left a caring role. This could suggest that worsening health may prevent some individuals from continuing their caring role, but further research is needed to reveal whether poor health *leads to* a person ending caring, or whether ending caring *is followed by* a decline in their health.

Housing issues for older carers

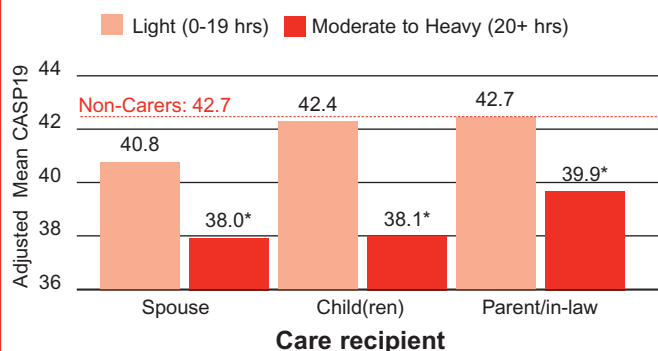
Not surprisingly, people looking after their spouse, and those providing moderate to heavy levels of care to a parent or parent-in-law, were more likely to have housing adaptations such as hand rails in the bathroom or a stair lift, than non-carers. People looking after their spouse were also more likely to have adaptations associated with a disability (eg, widened doorways, wheelchair ramps).

However, people caring for a spouse were less likely to own their own home than non-carers. In addition, those providing moderate to heavy care for a spouse or a child were slightly more likely than non-carers to experience housing problems (eg, shortage of space, lack of light, problems with insects, mice or rats).

Quality of life issues for older carers

Quality of life was measured using 'CASP19', which was specifically designed to measure well-being among the older population by constructing a score from a person's level of agreement/disagreement with 19 well-being statements (eg, 'I look forward to each day', 'I feel full of energy these days'). Figure 3 (below) shows that, on average, people providing moderate to heavy levels of care had a significantly lower quality of life than non-carers, regardless of who they were caring for. There were no significant differences between non-carers and those providing light levels of care.

Figure 3. A comparison of the quality of life of carers and non-carers (2004)



In order to identify potential areas for improvement, we also explored the influence of key social policy areas on carers' quality of life scores. Overall, health was the most important predictor of quality of life. Both self-reported health, and the ability to carry out a number of physical activities, showed the strongest relationship with carers' quality of life. Carers were healthier, on average, than non-carers. But this finding suggests that when health problems do occur, they have a severe impact on a carer's quality of life.

Other factors that had a significant detrimental impact on carers' quality of life included financial hardship, and problems accessing a number of services, especially a GP or shops. Having a hobby or pastime, taking a holiday in the UK and going on a day trip or outing were all found to be important for good quality of life.

How care recipients influence carers' well-being

In order to understand how a care recipient influences the well-being of a carer, we examined a range of factors, including:

- the level of care the recipient required (their ability to carry out a number of tasks associated with self care, and with living independently in a community);
- two measures of the recipient's health (their subjective health and whether they often experienced severe pain);

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- two measures of the recipient's cognitive ability, including a measure of their memory.

We were only able to examine for the impact of these on people caring for their spouse.

Memory function in a care recipient was the greatest predictor of the well-being of the carer: other aspects of the care relationship, including the person's physical needs, were not as important to the carer's well-being as the person's ability simply to remember things. We also took account of the number of care hours the carer was providing and whether they had to care for more than one person.

It is possible that someone with a poor memory could be exhibiting early signs of dementia or Alzheimer's, which is likely to cause great anxiety and burden to the caring spouse. However, this link is only hypothetical as our only record of dementia or Alzheimer's was for those cases which had been diagnosed by a GP.

Implications for policy

As this research shows, older carers who are providing 20 or more care hours a week have significantly worse quality of life than non-carers. Evidence from this report suggests there are a number of areas in which the lives of older carers could be significantly improved.

For some care groups, notably those providing care to a child or a spouse, there is some suggestion for the need for greater financial support to ensure that levels of material well-being remain consistent with the level experienced by non-carers. There is also the suggestion that current respite services might need to be re-evaluated in light of some of the disparities in both leisure and holiday experiences, particularly among those providing care for a spouse. These kinds of services might also be crucial in allowing carers better opportunities for carrying out everyday tasks such as visiting their GP or shopping.

This last point links with our findings on health. On the one hand, the better than average health found among carers could suggest that current health services are working so that carers' health is not being compromised. However, it is more likely that being healthy is a prerequisite for caring for others. Indeed we found some evidence linking worsening health with a move out of a caring role. This suggests that more may need to be done to ensure carers are better able to look after their own health (such as being able to visit their GP), as well as the health of the person they are

caring for. It also raises the question of what happens to the care recipient if their carer's health deteriorates.

Finally, the impact of a care recipient's memory function on their carer's quality of life may be attributable to the effect of the early stages of dementia or Alzheimer's. It is clearly important to ensure that carers facing these kind of difficulties are getting all the advice and support they need, which seems to underline the importance of the plans for 'memory clinics' to spot and treat dementia unveiled in the latest Government strategy.

Methodology

The findings from this study are based on two waves (2004 and 2006) of the English Longitudinal Study of Ageing (ELSA). ELSA is a study of people aged 50 and over, and is managed as a collaboration between NatCen, University College London and the Institute for Fiscal Studies (IFS). Funding for ELSA comes from the National Institute on Aging in the United States, and a consortium of UK Government departments.

All the analysis includes adjustments for gender, age, marital status and education. This is a standard approach in statistical analysis to ensure that any differences found, in this case between carers and non-carers, are not attributable to common demographic differences. Some of the analysis also includes additional adjustments, for example, the analysis exploring difficulties in accessing services includes adjustments for physical mobility, and whether the person had access to a car. Further information detailing the methods used in this research is given in the full report.

Obtaining the full report for this study

The full report of these research findings, *Living and Caring* by Andy Ross, James Lloyd, Michael Weinhardt and Hayley Cheshire (2008) was published by the International Longevity Centre-UK in September 2008. It can be downloaded for free from the website:

www.ilcuk.org.uk

For more information on this research, please contact Andy Ross: A.Ross@natcen.ac.uk

For general enquires about ELSA, please contact Kate Cox: K.Cox@natcen.ac.uk